



General

Guideline Title

Nursing management of the patient with multiple sclerosis.

Bibliographic Source(s)

American Association of Neuroscience Nurses (AANN), Association of Rehabilitation Nurses (ARN), International Organization of Multiple Sclerosis Nurses (IOMSN). Nursing management of the patient with multiple sclerosis. Glenview (IL): American Association of Neuroscience Nurses (AANN); 2011. 49 p. [268 references]

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

The levels of recommendation (1-3) and the levels of evidence supporting the recommendations (I-IV) are defined at the end of the "Major Recommendations" field.

Definition, Natural History, and Epidemiology of Multiple Sclerosis (MS)

The model of nursing care in MS includes establishing, continuing, and sustaining care along the MS spectrum of new or probable MS, relapsing forms of MS, progressive MS, and advanced MS (Level 3). Nurses should facilitate treatment and symptom management, promote and enhance function, and support a quality of life (QOL) of adults with MS and their family-care partners that is wellness focused (Level 3). Nurses use evidence-based knowledge to determine an effective course of action for MS patients with specific needs (Level 2). Nurses act as advocates to ensure that patients and their family-care partners have access to needed care and assistance in using resources crucial to managing MS (Level 2). Nurses should help patients locate and develop appropriate resources and initiate contacts as needed (Level 2).

Classification of MS

Nurses caring for patients with MS need an understanding of the various types of MS and should be familiar with the typical clinical course of each type in order to:

- Provide explanations and initiate patient education and counseling for patients and their families
- Provide information and counseling to help patients and care partners develop a realistic picture of the disease, the benefits of treatment, and expectations related to its management
- Help patients and their families cope with a new diagnosis of MS, adopt a healthy lifestyle, and maintain a positive and hopeful perspective

- Emphasize health-promotion strategies and preventive health care and screening, including the importance of regular follow-up with their neurologist and other healthcare providers (Level 3).

Immunogenetics and Pathogenesis

Well-designed multidisciplinary research is needed for a more complete understanding of the pathophysiology of MS (Level 3).

Assessment and Diagnostic Process

Assessment

A comprehensive assessment should be completed, including the following areas: physical, cognitive, sensory, and bowel and bladder function. The baseline functional assessment can be used to compare with future neurologic examinations (Level 2). For assessment of function, frequency of evaluation has not been extensively studied. Nurses should complete an initial assessment of function and monitor on an ongoing basis for any changes in condition (Level 3).

Diagnosis

Nurses should familiarize themselves with published and ongoing research efforts in the area of biomarkers for MS disease diagnosis and progression to provide patient education regarding laboratory testing and respond to questions from patients (Level 3).

Disease Management

Management of MS

Nurses need to be aware of the mechanism of action of MS medications to educate and counsel patients about expected benefits and adverse effects of medication therapy (Level 3). Nurses need to be aware of the role of personal patient preference and drug regimen complexity related to tolerance of and willingness to adhere to treatment protocols (Level 2).

Economic Considerations

Nurses can serve as advocates for MS patients related to ensuring connection with medication support services (Level 2).

Immunotherapies Reveal Aspects of MS

Nurses must be aware of patient responsiveness to therapy and serve as advocates for follow-up with appropriate interdisciplinary team providers (Level 3). Nurses should monitor MS patients for medication-related side effects and use appropriate strategies to manage their manifestations (Level 2).

Clinical Features and Symptom Management

Clinical Features and Sensory Symptoms

The nurse should conduct intermittent assessment for pain, dyesthesia, and spasticity (Level 2). Evaluate for the loss of neuroprotective sensation and the potential for pressure ulcer development (i.e., ensure full body assessment; Level 2). Evaluate the patient for triggering and alleviating factors (Level 2). Evaluate the effectiveness of pharmacologic therapies and advocate for evaluation by the interdisciplinary team (Level 1). Provide patient with emotional support and evaluate for anxiety (Level 2). Provide patient and family education related to availability of adjuvant treatment and possible surgical interventions; assess patient's willingness and readiness to incorporate alternative therapies into treatment regimen (Level 3).

Visual and Hearing Impairment

Encourage regular eye examinations (Level 3). Be aware of the potential for hearing changes and assess as needed (Level 3). Provide education regarding the patient's particular visual and hearing symptom experience (Level 3). Support the patient as visual and hearing impairment may reduce overall function (Level 2). Promote safety through education and counseling related to effective lighting, scanning, and environmental modifications (Level 2).

Fatigue

Nurses should be aware of and assess for secondary causes of fatigue to include depression, medication side effects, pain, and sleep disorders (Level 2). Nurses should educate and counsel patients regarding energy conservation strategies, including the role of body temperature control (Level 2). The nurse should be aware of the optimal timing of medication administration to enhance energy level and to avoid interrupting sleep

(Level 3).

Impaired Mobility

Identify functional effect of impaired mobility and collaborate with interdisciplinary team members to promote optimal mobility within the patient's limitations (Level 3). Evidence-based treatment interventions for mobility optimization include exercise promotion (Level 1). Educate patient and care partners regarding treatment, therapy recommendations, medications, and support adherence (Level 3). The nurse should encourage safety by reinforcing appropriate and safe use of adaptive equipment and aides (Level 2). Assess for the psychological effect of reduced mobility and/or increased disability (Level 2).

Bladder and Bowel Symptoms

Nurses should work with the patient, care partner, and other members of the interdisciplinary team to develop an appropriate bladder management program (Level 3). Assess all patients for urinary dysfunction and assess effectiveness of treatments or behavioral strategies over time (Level 3). Encourage discussion of symptoms and effect on QOL and role function and assist with coping strategies (Level 3). Assess for infection and assist in management strategies to reduce risk of infection, stone formation, or worsening of neurologic condition (Level 3).

Nurses should work with the patient, care partner, and other members of the interdisciplinary team to develop an appropriate bowel management program (Level 3). Assess all patients for disorders of bowel function and assess effectiveness of treatments or behavioral strategies over time (Level 3). Encourage discussion of symptoms and effect on QOL and role function and assist with coping strategies (Level 3). Assess for effectiveness of management strategies and effectiveness of medications, understanding that bowel interventions may take a long time to become effective and that worsening of symptoms without any relief from strategies may indicate disease progression (Level 3).

Sexual Dysfunction and Reproductive Issues

Nurses must consider MS patients' interest in sexuality and intimacy rather than assume that they are asexual or uninterested (Level 2). Nurses should provide information, education, counseling, and resources about issues related to sexuality, reproductive function, pregnancy, and parenting (Level 3).

Dysphagia

Assess the patient regularly for swallowing difficulties (Level 2). Nurses should work with the patient, care partner, and other members of the interdisciplinary team to develop an appropriate dysphagia management program (Level 3). Monitor weight at each visit (Level 3). Educate and counsel the patient and care partner to reinforce safe swallowing practices (Level 3).

Cognitive Dysfunction

Nurses should work with the patient, care partner, and other members of the interdisciplinary team to develop an appropriate cognitive management program and reevaluate on an ongoing basis (Level 3). The nurse should screen for factors that could increase cognitive problems such as medications, sleep disturbance, inadequately treated pain, and other untreated symptoms (Level 2). Nurses need to recognize and acknowledge the distressing nature of cognitive deficits (Level 3). Patients should be provided with verbal and written instructions regarding the need to reduce distractions and implement safety measures (Level 3).

Mood Dysregulation

Nurses should work with the patient, care partner, and other members of the interdisciplinary team to manage depression appropriately (Level 2). Other roles are to assist patients and care partners to adjust to changes involved in living with MS (Level 2); identify the physical, emotional, spiritual, and educational needs of the patient and family (Level 2); reinforce the importance of medication regimen and be aware of medication side effects (Level 2); be alert to cues related to mood changes and treatment outcomes (Level 2); and encourage participation in a regular pattern of exercise to improve mood (Level 1).

Patient and Care Partner Education

Nurses should use an evidence-based and wellness-focused approach to education and counseling to assist patients with MS and their families to adhere to the treatment regimen, manage their symptoms, and cope with their chronic disease (Level 3). The nurse should screen for factors that could influence the ability to learn, such as cognitive difficulties and health literacy issues, and adapt teaching as appropriate (Level 2).

Definitions:

Levels of Evidence Supporting the Recommendations

Class I: Randomized controlled trial (RCT) without significant limitations or meta-analysis.

Class II: RCT with important limitations (e.g., methodological flaws or inconsistent results) or observational studies (e.g., cohort or case-control).

Class III: Qualitative studies, case study, or series.

Class IV: Evidence from reports of expert committees or expert opinion of the guideline panel, standards of care, and clinical protocols.

Levels of Recommendation

Level 1: Recommendations are supported by class I evidence.

Level 2: Recommendations are supported by class II evidence.

Level 3: Recommendations are supported by class III and IV evidence.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Multiple sclerosis (MS)

Guideline Category

Counseling

Diagnosis

Evaluation

Management

Risk Assessment

Screening

Treatment

Clinical Specialty

Family Practice

Internal Medicine

Neurology

Nursing

Physical Medicine and Rehabilitation

Intended Users

Advanced Practice Nurses

Hospitals

Nurses

Guideline Objective(s)

To offer evidence-based recommendations on nursing activities that have the potential to maximize outcomes for adults with multiple sclerosis (MS)

Target Population

Patients with multiple sclerosis (MS)

Interventions and Practices Considered

1. Establishing, continuing, and sustaining nursing care along the multiple sclerosis (MS) spectrum of new or probable MS, relapsing forms of MS, progressive MS, and advanced MS
2. Understanding the clinical course of the various types of MS in order to provide appropriate patient education and counseling, health-promotion strategies, and preventive health care and screening
3. Comprehensive assessment of physical, cognitive, sensory, and bowel and bladder function
4. Familiarization with research in the area of biomarkers for MS disease diagnosis and progression to provide patient education regarding laboratory testing
5. Education and counseling patients on medication benefits and adverse effects
6. Serving as patient advocate for follow-up with appropriate interdisciplinary team providers
7. Monitoring and managing MS patients for medication-related side effects
8. Management of clinical features and symptoms related to:
 - Sensory symptoms
 - Visual and hearing impairment
 - Fatigue
 - Impaired mobility
 - Bladder and bowel symptoms
 - Sexual dysfunction and reproductive issues
 - Dysphagia
 - Cognitive dysfunction
 - Mood dysregulation
9. Strategies related to patient and care partner education

Major Outcomes Considered

- Patient and caregiver physical, social, economic, and psychological responses to nursing management approaches to multiple sclerosis (MS)
- Prognostic factors associated with specific disease types
- Effectiveness of communication and health promotion strategies for patients and caregivers
- Value of baseline and ongoing diagnostic assessments and tools, including lab biomarkers
- Benefits and adverse effects of medications
- Cost-effectiveness of treatment options
- Effectiveness of assessment and management strategies for:
 - Vision and hearing impairment
 - Fatigue
 - Optimal mobility
 - Bladder and bowel function

- Swallowing difficulties
- Cognitive abilities and changes
- Depression related to MS
- Effectiveness of evidence-based patient and caregiver education

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

A computerized search of MEDLINE, Cochrane, and the Cumulative Index to Nursing and Allied Health Literature was performed by using *multiple sclerosis*, *symptom*, *disease management*, *nursing*, and *education* as keywords. The search was restricted to works in English and adults. The reference lists of identified articles were also searched for additional, relevant references including books, guidelines, and articles.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Levels of Evidence Supporting the Recommendations

Class I: Randomized controlled trial (RCT) without significant limitations or meta-analysis.

Class II: RCT with important limitations (e.g., methodological flaws or inconsistent results) or observational studies (e.g., cohort or case-control).

Class III: Qualitative studies, case study, or series.

Class IV: Evidence from reports of expert committees or expert opinion of the guideline panel, standards of care, and clinical protocols.

Methods Used to Analyze the Evidence

Systematic Review

Description of the Methods Used to Analyze the Evidence

A panel of nursing experts determined the level of evidence for each study included in the guideline, summarizing the level of evidence for each recommendation (see the "Rating Scheme for the Strength of the Evidence" and the "Rating Scheme for the Strength of the Recommendations" fields).

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

The Clinical Practice Guidelines recommendations for practice are established based upon the evaluation of the available evidence. Resources and recommendations must describe the best practices that can enable registered nurses (RNs) to provide optimal care for persons with multiple sclerosis (MS).

Rating Scheme for the Strength of the Recommendations

Levels of Recommendation

Level 1: Recommendations are supported by class I evidence.

Level 2: Recommendations are supported by class II evidence.

Level 3: Recommendations are supported by class III and IV evidence.

Cost Analysis

Economic Considerations

1. Financially, disease-modifying treatments (DMTs) can be costly and a significant burden to patients and families. Both direct and indirect costs may or may not be reimbursed by insurance plans, which vary individually. One published study estimated current costs and quality of life (QOL) of patients taking disease-modifying medications, the total average annual cost in 2004 was \$47,215 (U.S. dollars) per patient. Of the total average cost, it was determined that 53% was for direct medical and nonmedical costs, while 37% was related to losses in productivity, including short-term absence, reduced working time, and early retirement. Approximately 10% of the yearly costs were attributed to informal care. Costs were significantly correlated with functional capacity.
2. Affordability of disease-modifying agents: Studies have shown that some medications may be more affordable than others. Newer medications would likely be more expensive than existing ones that have been used for a longer time. Natalizumab (Tysabri®) has been shown to reduce relapses and slow disease progression, but the assessment of lifetime cost-effectiveness of natalizumab versus other disease-modifying drugs is inadequate. One research report shows that direct costs (remaining lifetime) for patients receiving glatiramer acetate or natalizumab compared to costs associated with symptom management were only \$408,000; \$422,208; and \$341,436, respectively. Glatiramer acetate was more cost-effective than natalizumab. Long-term evidence showed that glatiramer acetate has similar, if not improved, clinical benefits, despite 1- and 2-year relapse rates being better for natalizumab.
3. Relapsing remitting multiple sclerosis (RRMS) affects the majority of the MS population. Although there are several disease-modifying therapies (DMTs) for RRMS, not all are available for the same cost. One study analyzed the 2-year effectiveness of four DMTs used for RRMS—glatiramer acetate, interferon (IFN) β -1a intramuscular injection, IFN β -1a subcutaneous injection, and IFN β -1b subcutaneous injection. Variables included relapses, disability progression, and direct medical costs. Medical savings were considered in an event of an avoided relapse and disability progression prevention. It was found that without DMT, patients had more relapses and pronounced disability progression. The four DMTs previously mentioned are the most cost-effective treatments for RRMS.

Method of Guideline Validation

Peer Review

Description of Method of Guideline Validation

The guideline underwent peer review by a panel of reviewers listed in the guideline document.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Appropriate nursing strategies for the management of multiple sclerosis (MS)

Potential Harms

Nurses should monitor multiple sclerosis patients for medication-related side effects and use appropriate strategies to manage their manifestations.

Qualifying Statements

Qualifying Statements

- The authors, editors, and publisher of this document neither represent nor guarantee that the practices described herein will, if followed, ensure safe and effective patient care. The authors, editors, and publisher further assume no liability or responsibility in connection with any information or recommendations contained in this document. These recommendations reflect the judgment from the American Association of Neuroscience Nurses (AANN), the Association of Rehabilitation Nurses (ARN), and the International Organization of Multiple Sclerosis Nurses (IOMSN) regarding the state of general knowledge and practice in the field as of the date of publication and are subject to change based on the availability of new scientific information.
- Adherence to these guidelines is voluntary, and the ultimate determination regarding their application must be made by practitioners in light of each patient's individual circumstances. This reference is an essential resource for nurses providing care to the adult patient with multiple sclerosis (MS). It is not intended to replace formal learning but rather to augment clinicians' knowledge base and provide a readily accessible reference tool. The nursing profession, AANN, ARN, and IOMSN are indebted to the volunteers who have devoted their time and expertise to this valuable resource, which was created for those who are committed to excellence in the care of patients with MS.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Implementation Tools

Resources

Staff Training/Competency Material

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

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Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2011

Guideline Developer(s)

American Association of Neuroscience Nurses - Professional Association

Association of Rehabilitation Nurses - Professional Association

International Organization of Multiple Sclerosis Nurses - Professional Association

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Guideline Committee

Not stated

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Financial Disclosures/Conflicts of Interest

A staff member, volunteer or family member who has an affiliation with a commercial company must declare that relationship in advance of involvement with an education activity that could be used as a forum to promote interest of that company and its products. None of the authors or planners has anything to disclose related to this activity.

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the [American Association of Neuroscience Nurses Web site](#) .

Availability of Companion Documents

The following are available:

- Nursing Management of the Patient with Multiple Sclerosis - CPG online exam. Available from the [American Association of Neuroscience Nurses Web site](#) .
- Putting guidelines into practice: Care of a Patient with Multiple Sclerosis. CPG Web cast. Available from the [American Association of Neuroscience Nurses Web site](#) .

Patient Resources

None available

NGC Status

This NGC summary was completed by ECRI Institute on September 26, 2012. The information was verified by the guideline developer on October 14, 2012.

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